REHABILITATION

A development challenge

A King's Fund Working Paper

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King's Fund

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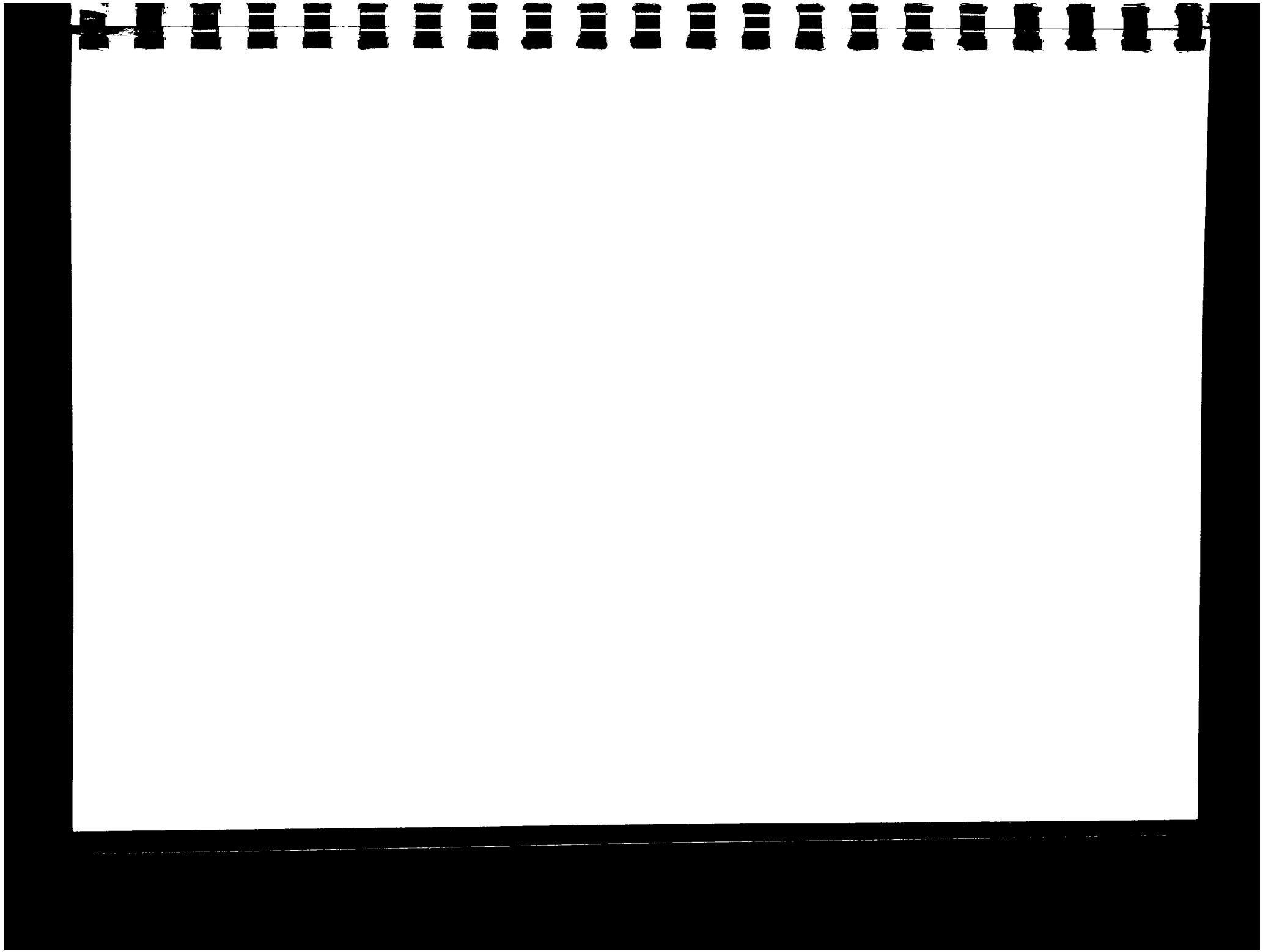

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Executive Summary

1. Introduction

This working paper focuses upon opportunities for rehabilitation within a spectrum of support required by people who are ill or disabled. It provides insights into common perceptions of shortcomings in the current system of rehabilitation and of the potential benefits which would arise from additional investment in this aspect of care. It discusses the significance of these perceptions for the development of policy and practice in this area. The paper then goes on to suggest courses of action that might be taken at national and local level to further the strategic development of services facilitating rehabilitation.

The paper draws on consultations held in the summer of 1996.

2. Common Concerns and Experiences of Rehabilitation

Our consultations reveal serious concerns about shortcomings in the current health and social care system but the overall picture is by no means bleak. Good practice developments, together with a broad commitment to improve the current system, are evident. Major themes arising from our consultations were as follows:

- **Lack of a shared understanding of the term `rehabilitation'** can lead to confusion, misunderstanding and heated debate about what it involves, who benefits, who enables it to take place and where.
- **Service users and their families are believed to be experiencing difficulties** as a result of declining opportunities for rehabilitation. Older people are seen as being particularly disadvantaged, with carers being left to support relatives who are more dependent than is necessary.
- **Rehabilitation is seen as having had low priority** in the overall health and community care policy agenda. . Both health and social services are perceived to be afflicted by a dependency culture that mitigates against proactive rehabilitation.

- **Organisation of rehabilitation is seen to be inhibited by poor co-ordination** and inappropriate competition between professionals and agencies. Joint commissioning to date has produced what are perceived to be disappointing results.. Difficulties in recruiting and retaining specialist staff are reported and it is felt that generalist staff are not encouraged to play a more effective role in rehabilitation.
- **There are worries that investment in rehabilitation will stall** when evidence of effectiveness is weak or inaccessible. Most providers and purchasers are believed to know little or nothing about the research that has been undertaken into aspects of rehabilitation practice.
- **There are encouraging signs of service developments** including new schemes and projects designed to fill gaps in provision. A broad consensus is evident about principles of good practice in rehabilitation.

2. Reflections on Key Themes

The views expressed during consultations need to be considered in the context of changing policy environments, the perspectives of different interest groups and evidence that might confirm or challenge common perceptions.

- **Financial pressures are causing rehabilitation to move up the policy agenda.** There are increasing concerns about escalating expenditure on services for older people and a belief that greater investment in rehabilitation will achieve overall cost savings or, at least, be more cost-effective. Increased investment would prevent the NHS and local authorities from being locked into unnecessarily high levels of expenditure associated with frequent readmissions to hospital, resettlement in nursing or residential care homes and complex packages of domiciliary care.
- **There is little hard evidence to support the notion that opportunities for rehabilitation have been declining** or that increased investment in this aspect of care will offer cheaper or more cost-effective options. Nevertheless, the case for investing in rehabilitation has been given a boost by the Department of Health's guidance on continuing care, by the House of Common's Health Committee's investigation into the

funding of long term care and various inquiries into intermediate care and preventative services.

- **A clear conceptual framework is needed** mapping out the key components and core principles of rehabilitation. Creating a better map of the rehabilitation 'territory' would help to clarify more precisely what it is that needs to be improved and to focus developmental activity on those areas identified as being particularly problematic.
- **Greater efforts are required to hear the stories of users and carers**, in order to understand more clearly what, from their point of view, is working well and where there is room for improvement. These stories may confirm what professionals are saying but they may also challenge the claims being voiced by some professionals.
- **A user or patient-centred focus is necessary** if we are to move away from historic patterns of rehabilitation. Good outcomes for service users will depend upon effective liaison and joint working across professional and agency boundaries.
- **There is a complex planning and development agenda which needs to be taken forward** at national and local levels in order to achieve success in improving the range, availability and quality of rehabilitative services. Both health and social care commissioners are under pressure to base their investment strategies on evidence of effectiveness and value for money. Where that evidence is weak or inaccessible, it will be hard to justify changes in existing patterns of expenditure. It will therefore be important to disseminate evidence on organisational arrangements and professional practices that have been found to achieve effective outcomes for individuals and for the agencies involved.
- **Claims of shortages in specialist staff** need to be viewed with caution. It may be more profitable to re-examine roles, responsibilities and relationships between specialists and generalists. There is scope for exploring how specialists in rehabilitation medicine and allied therapies can be better placed to advise, educate and supervise others (including nursing staff, care assistants and family carers) in therapeutic activities. Changes in the education and training of health and social care staff will be required to improve awareness, knowledge and skills.

3. Moving Towards a Rehabilitation Development Agenda

We conclude that the time is right to embark on a programme of work that aims to enhance opportunities for rehabilitation in a way that avoids reliance on ad hoc, opportunistic service development. Further work is needed to ensure that future development initiatives are conceptually sound, focused on clear and achievable goals and capable of attracting support from the many political, managerial, professional and lay interests who have a stake in this aspect of care.

A two stage programme of work is proposed.

Stage One will help shape a subsequent development strategy. It involves:

- **a literature review** to help identify a conceptual framework needed to inform future action and to consider the evidence regarding responsibilities, trends and effectiveness in rehabilitation
- **further consultations with users and carers** in order to involve them more fully in future developments
- **collecting examples of service models** that are being put in place and analysing their significance for strategic service development.

Stage Two

- **a nation-wide service development initiative** encouraging local agencies to test out new ways of working and to implement schemes of proven worth
- **a network** for the exchange of information and ideas on innovation and good practice
- **a dissemination strategy** to transmit news of work in progress and lessons being learned.

The King's Fund aims to take forward this programme, in partnership with other interested national, regional and local bodies.

INTRODUCTION

This paper focuses on rehabilitation - an aspect of care that is currently attracting great interest among health and social service agencies. It is a discussion paper which:

- explores current concerns regarding opportunities for rehabilitation within the present service system,
- reflects on the significance of those concerns, and
- suggests courses of action to address problems arising.

We have focused on rehabilitation, recognising that it is a key component of the support required by people whose independence has been impaired by illness, injury or accident. As we discuss later, there are many interpretations of what constitutes "rehabilitation" but, as we have embarked on our exploration, we have adopted a simple starting point which distinguishes rehabilitation from acute and long term care. Thus, we see rehabilitation as a process located in a continuum of care, sitting alongside acute interventions where the aim is to cure, and long term care with its emphasis on maintenance. In contrast, rehabilitation involves the restoration of well-being and independent living to optimum levels.

Our decision to investigate this aspect of care arose from our experience of working in a variety of development projects concerned with improving services for people who are ill or disabled. Through our contact with service users, carers, practitioners and managers, we became aware of increasing dissatisfaction about access to rehabilitation opportunities within the current health and social care system. Concerns were being expressed about the stresses and strains which resulted for service users and their families, and indeed for some service providers.

As observers of developments taking place on the health and social care boundary of community care, we had also been aware of controversies throughout the 1990s about NHS responsibilities for people with continuing care needs. Mounting concerns about the NHS withdrawing from various aspects of care required by this group of patients had been countered by departmental guidance reaffirming NHS responsibility for a range of provision, including rehabilitation, and encouraging investment or reinvestment in these areas. When we embarked on this investigation, the impact of that guidance on the development of rehabilitation was not known. However, we were aware that many health service commissioners were uncertain about the investment strategies required for the development of rehabilitation provision.

By 1996, we also recognised that a certain "head of steam" was building up around the issue of rehabilitation, with a great deal of interest in the topic being demonstrated by organisations such as the Audit Commission, the Social Services Inspectorate, the NHS Executive and Department of Health, and by professional associations like the British Geriatrics Society. A range of problems concerning rehabilitation was becoming apparent, accompanied by emerging expectations that rehabilitation might be the solution to critical problems afflicting the NHS and local authorities alike. These problems related to escalating costs and perceived blockages in the service system. This situation demanded further investigation in order to find out more about the problems arising and to consider what might be done to help tackle difficulties identified.

We began our investigation in the summer of 1996 by listening to what people were saying about rehabilitation. In co-operation with the NHS Executive, the Social Services Inspectorate and the Audit Commission, we brought together a group of people from very different backgrounds so that they could air their concerns, describe their experience of innovation and good practice in this area and discuss their ideas for addressing problems identified. The group included people with disabilities, practitioners with medical, nursing, therapy and social work backgrounds, managers responsible for providing or commissioning services, policy advisers and academics.

In section 1 of this paper, we set out the concerns and ideas of this group. What they say about rehabilitation necessarily entails their views, perceptions and opinions. In section 2, we reflect on the views expressed, exploring their significance for policy and practice. And finally, section 3 puts forward suggestions for action needed to advance the development of rehabilitative provision.

frustration with the difficulties they had experienced in gaining acceptance for more holistic approaches.

A Suitable Term?

Finally, the language of rehabilitation seemed to cause some unease. Some people saw it as a very old-fashioned, unattractive and misleading word. The term clearly has historical associations with wartime injury and with accidents in heavy industry like coalmining. While some people seemed to feel comfortable using the term, others struggled to avoid it and used other terms like "support for independent living".

CURRENT CONCERNS ABOUT REHABILITATION

The main themes that emerged centred around stresses and strains currently being experienced by service users and their families; the lack of any clear policy drive; adverse conditions in the current organisation of care, and the influence of research on commissioning activity and routine practice.

The Experiences And Expectations Of Users And Carers

Time To Recover

There were worries that early discharge from hospital is leaving insufficient time for people to recover from surgical and medical interventions. This applies especially to older people, who were seen as needing more time to recover from illness or injury and more time to regain, as far as possible, the confidence and skills needed to return to the life they had before admission to hospital. Claims were made that many people still expect to be offered a period of convalescence in places other than a hospital or their own home - and they are surprised and dismayed to find that few alternatives are currently available. The main concern here was that, with little or no back-up in the home, family carers are being left to cope alone with the responsibility of supporting their relatives in the short, and often longer, term.

Poor Access

Disabled people believed that their access to rehabilitation varies according to where they live and they considered this variability to be unfair. Complaints were also made that while, in some cases, it is possible to have short bouts of intensive rehabilitation in hospital, there is often insufficient follow through in the community and rarely opportunities for more prolonged periods of continuous or periodic therapy for those with long term and fluctuating illness or disability. Vocational assessment services were seen as poor, thus exacerbating the worries of people who have become disabled that they may lose their job. Older people were thought to be at a particular disadvantage, with access to rehabilitation opportunities restricted by discriminatory, ageist attitudes placing greater value on the lives of younger people, who are more likely to be economically active.

Service deficits

The practice of providing rehabilitation opportunities in hospital environments rather than in more homely settings was questioned. There was agreement that there are insufficient community-based services capable of facilitating the rehabilitation of people in the homes and neighbourhoods where they live.

There was a common view that it is unusual to find approaches to rehabilitation that entail long term monitoring allowing early intervention and prevention of crises. The prevailing approach tends to focus on short episodes of therapy, where the individual is 'signed off' at the end of specific treatments. This was considered to be unhelpful to people with long term illness or disability, whose circumstances can change incrementally or dramatically over periods of time.

SECTION ONE

DISCUSSIONS ABOUT REHABILITATION - What people are saying

How People Talk About Rehabilitation

During the course of discussions held, it was clear that while everyone knew what he or she meant by "rehabilitation", their interpretation was not necessarily shared by others. Meanings differed according to what is involved, who benefits, who provides opportunities for rehabilitation and where.

What Is It?

Some people spoke about rehabilitation as if it were a time-limited "treatment". Others talked about it as a process of continuous review, reassessment and renewed interventions for changing circumstances. While rehabilitation was usually portrayed as a process rather than a service, reference was frequently made to "rehabilitation services", identified as those staffed by specialists in rehabilitation medicine or in physio, occupational and/or speech and language therapy. These services were, more often than not, associated with discharge from hospital and largely accessed through hospitals, either on an in-patient or out-patient basis. This is not to say that community-based rehabilitation services did not feature in discussions, but that, time and time again, developments in hospitals - and their consequences for people in the community living at home - predominated.

Who Benefits?

When it came to the kind of people who might benefit from rehabilitation, there was widespread agreement. Potential beneficiaries were seen as people who have recently had a traumatic injury resulting in, for instance, serious head injury, spinal injury or a broken hip following a car crash or an accident like a fall, or a traumatic illness resulting in, for

instance, a loss of mobility and speech following a stroke. People with chronic, long term illnesses and disabilities were also included, for example those with neurological disorders such as Parkinson's Disease or multiple sclerosis, those with arthritis or cardiorespiratory diseases and those who simply "fail to thrive" and are often described in the health service as "off legs".

While most people tended to focus on examples related to physical injury and illness, there was a recognition that rehabilitation was also relevant to people with mental illness. At the same time, there was hesitation about including people with learning difficulties or, indeed, anyone born with a disability or acquiring it at an early age. Most people appeared to distinguish between rehabilitation, with its restorative function, and the development and education required by people disabled from birth as they grow into adulthood and are prepared for living independently in the community (sometimes called "habilitation"). In the case of people with learning disabilities, the term rehabilitation tended to be used solely in the context of transitions from long stay institutions to community living.

What Kind of Rehabilitation?

During discussions, people's awareness of different models of rehabilitation became apparent. Furthermore, strong allegiances or criticisms of particular approaches were expressed. Thus, reference was made to a "medical model", where emphasis is placed on prescribing specific professional interventions which return the passive individual to a more normal level of functioning. In a "social model", individuals were perceived to play a more active role in choosing courses of action that enable them to achieve preferred life-styles. That almost always entails tackling social and environmental barriers to independent living. For some, the medical/social model dichotomy was seen as unhelpful, with both approaches needing to be integrated into an "holistic" rehabilitation that addresses all relevant aspects of a person's life, in all its psychological, physical, social, economic and environmental dimensions. Where emotions ran high about these different models, there were usually accompanying stories by disabled people who felt they had been at the wrong end of unhelpful approaches, and by practitioners who expressed

Policy Directions

Priority Ranking

Most people regarded rehabilitation as having low priority in the overall health and community care policy agenda. While there was awareness of recent policy statements acknowledging the importance of rehabilitation, there was considerable scepticism about any real commitment to develop better provision. This stemmed from a widespread belief that commissioners and providers of health and social services continue to commit relatively low, and decreasing, levels of investment to rehabilitative provision. Furthermore, as finances become tight, rehabilitative services were perceived as being one of the first to be cut back.

In the NHS, more pressing priorities were seen to prevail, including waiting list initiatives and the imperative to comply with the efficiency index. In social services, policies targeting those in most need were seen as leading to reduced emphasis on prevention and surveillance, and a greater focus on looking after people who are assessed as having high levels of dependency.

Dependency Culture

Professionals and service users alike considered that, in practice, too much emphasis is being placed on 'minding' people with long term illness or disability rather than enabling them to live lives which offer greater independence, control and choice. This mind-set - depicted as 'minding but not fixing' results in a dependency culture that is perceived to afflict the delivery of both health and social services, most especially with regard to the care of older people. This is at odds with policy statements revealed in community care plans, joint planning documents and the like. This perceived dissonance between policy and practice may merely be indicating the length of time it takes to implement recently developed policies, but equally it was seen by some as evidence of weak and half-hearted policy direction. Certainly, people working in social services and in the NHS were concerned about a lack of any clear policy drive on rehabilitation and a situation where they believe their own authorities no longer have an 'active rehabilitation agenda'.

Disincentives

Policy development regarding rehabilitation was portrayed as being bedevilled with arguments about the respective responsibilities of the NHS and local authorities. Local authorities were reported to be cautious about being more proactive in developing rehabilitation services, at a time when the NHS has been accused of neglecting its responsibilities and passing on the costs of faster hospital through-puts to local authorities. Perceptions of cost-shunting were not thought to be helping the development of coherent policies on rehabilitation.

Organisational Considerations

Co-ordination

Concerns about lack of service co-ordination were common, being particularly acute in the case of people with neurological conditions such as MS, Parkinson's Disease or head injury. Stories were told of people being passed from pillar to post, with little counselling for patients and carers alike, and of "too little, too late". Inadequate co-ordination, between hospital departments and clinical specialisms, and between hospital and community services, was seen as one of most pressing problems in the organisation of rehabilitative services. The cause of the difficulty was explained by inadequate systems and procedures governing the overall management of support required by individuals and their families and by a failure to adopt care management and team work approaches, with the result that service users and carers have to struggle to make the necessary connections. Efforts to improve co-ordination by commissioning services related to specific diseases or disabling conditions, eg: stroke, were welcomed but were felt to be no solution for people with multiple and complex disabilities, nor, indeed, for those with rare conditions.

Market Effects

Fragmentation of the service system was thought to have increased with the development of the NHS internal market and the local authority mixed welfare economy. While there were many supporters of the separation of purchasers and providers, the achievement of commissioners in bringing about better patterns of care was seen as disappointing. Furthermore, people claimed that the development of good rehabilitative care has been greatly hindered by inappropriate competition between acute and community health trusts, who can see themselves as rivals in the 'same business'. They also saw few signs that GP fundholders have much of an interest in rehabilitation. Further more, there was a widespread suspicion that fundholders are inclined to be cautious in purchasing provision for people with long term illness or disability.

Working across boundaries

Professionals and service users alike pointed to the communication difficulties that seem to exist between acute, primary and community health services. These difficulties centred around admission and discharge arrangements which impair continuity of care and support as individuals move through the service system.

There were reports of rifts in some parts of the country between 'medical rehabilitation' (in the hospital) and 'social rehabilitation' (whatever is provided by social services, housing agencies, etc). Where these rifts were occurring, collaboration and team work simply could not exist; and rehabilitation was being financed, organised, managed and delivered in two entirely separate systems. Reference was made to encouraging signs of health and social services beginning to take an interest in the joint commissioning of rehabilitation and other continuing care services, but as yet there were disappointingly few examples of the two agencies tackling shared problems by, for instance, the joint commissioning of occupational therapy services, or of individualised rehabilitation packages.

People saw these boundary problems as being perpetuated by the way resources are currently allocated to particular institutions and sectors, rather than following the patient as he/she progresses through the health and social care system. With a large proportion of resources tied up in hospitals, they could see clear impediments to shifting rehabilitation into primary and community care services.

Employment, Education and Training

There were reports of shortages of rehabilitation specialists, particularly in medicine and in physio/occupational/speech therapies. Difficulties in recruiting some specialists - most especially physiotherapists - were explained by the availability of alternative and more attractive opportunities in the independent sector. Career development prospects within the NHS were considered to be limited, especially in view of the recent loss of many senior therapy manager posts. Difficulties were also reported in recruiting staff to work with older people, who are seen by some as less attractive and rewarding than the young people encountered in, for instance, sports injury clinics.

The deployment and management of those specialists currently employed also caused concern. Specialists do not always maximise their opportunities to advise and guide nurses, family carers and others concerned with the care of ill or disabled people - thus sharing their expertise and ensuring that therapeutic practices are built into everyday routine care.

When deploying occupational therapists, the boundary between health and social services was generally found to be unhelpful. Where OTs are employed by local authorities, most are considered to be far too heavily committed to assessing and providing home adaptations and equipment to have much time for therapeutic activities.

In many NHS trusts, where therapists are employed in a range of departments and units according to contract specifications regarding particular patient groups, some managers were reported to be in danger of losing sight of an overview of where specialists are located and how they might be rotated appropriately across departments, thus ensuring

more equitable resourcing of particular patient groups and improved opportunities for staff to broaden their knowledge and skills beyond the narrow confines of one department

Concern was expressed that education and training in rehabilitation is rarely multi-professional and hence fails to generate appreciation of the complementary roles of professionals and agencies. Clinical education was experienced as focusing on disease processes and symptom complexes and underplaying the purpose of rehabilitation and the development of generic skills.

Research and Evaluation

Evidence-based commissioning

At a time when commissioners are being encouraged to base their decisions on evidence of effectiveness, people were worried that investment in rehabilitation might decline by default because of an apparently poor research base and lack of robust objective measures of outcome.

Clinicians and researchers voiced particular concerns about the nature of research into rehabilitation, speaking of the difficulties they had encountered in gaining recognition and funding for qualitative studies that they considered more appropriate than randomised control trials. There was a strong body of opinion pointing out the limitations of control studies when rehabilitation does not aim to achieve biological norms, involves individualised packages of support with different personal goals, and depends critically upon the active participation and personal circumstances of the individual disabled person (and often, their carer).

Passionate arguments about the respective merits of quantitative and qualitative approaches took place during the course of these discussions and, while the technical details appeared to interest only a minority in the discussion group, there was nevertheless a more widely held view that the body of research into this aspect of care lagged behind the much larger amount concerning the efficacy of acute interventions.

Disseminating and Implementing Research Findings

Most people knew little or nothing about the research that has been undertaken into aspects of rehabilitation practice. Access to research findings is perceived to be difficult, because of the wide range of journals and databases in which information may be found (Medline, CINALH, ASSIA, etc), the absence of some of the relevant rehabilitation journals from those databases, and a relative dearth of reviews summarising relevant studies. Where evidence of effective practice is known, as in the case of people who have had strokes, there was a perception that transferring those findings into routine practice tends to be slow.

Experience of Innovation and Good Practice in Rehabilitation

While there were clearly many concerns about shortcomings in the current rehabilitation system, there were also encouraging signs of service development involving experimentation, the implementation of new ways of working and the setting up of new schemes or projects to improve rehabilitation opportunities.

When users, practitioners and managers were asked about good practice in rehabilitation, they had no hesitation in identifying service developments that they considered to be worthwhile and effective. They drew attention to a range of initiatives assisting in the rehabilitation of young and older disabled people. The schemes mentioned included an elderly resource team; day centre-based rehabilitation programmes; a 'back to work' service; early hospital discharge and support schemes; respite care incorporating assessment and rehabilitation; Independent Living Teams; OT-led health review clinics; nursing home-based rehabilitation support packages; link teams offering support to users and their carers; transitional housing following discharge from hospital or residential home and community based outreach rehabilitation teams.

Recognising Good Practice

Few of the schemes and projects described as good practice developments had been subject to any formal evaluation assessing their effectiveness or their relative value as compared with other related forms of provision. However, as people talked about their experience of innovation and good practice in rehabilitation, it was clear that findings from research studies were only one of a variety of means used to identify effective approaches in rehabilitation.

Commonly, a process of review and reflection seems to be used, which enables practitioners and managers to understand why some initiatives succeed while others fail. This was most apparent in discussions about setting up and running new services or facilities. Success or failure were seen as highly dependent upon the relationships forged between different professional groups, different agencies and different care sectors. Failures to involve the right mix of people in planning and developing rehabilitation services were identified as `bad practice' and crucial in explaining why some service developments had run into difficulties and even collapsed altogether. Similarly, designing a service with unclear goals and having insufficient expertise to deal with people with multiple and complex disabilities was seen as contrary to good practice. Much was made of the value of this review process, where important lessons are learned, shortcomings are identified and addressed while building on progress being made.

When it came to identifying good practice in working directly with individual service users and their families, assessing their needs and providing practical help and support, judgements on effective approaches might be informed by information gained from service users (mainly through surveys of users' opinions and experiences), from guidelines issued by professional bodies and, to a very limited extent, from the findings of research studies. It was notable that great reliance was placed on `common sense' when recognising good practice. This applied particularly to observations of behaviour towards and communications with service users, where partnership approaches were considered to be more effective than professional paternalism.

The Dimensions of Good Practice in Rehabilitation

During discussions about effective approaches in rehabilitation, a range of issues emerged which were seen as central to the design and delivery of a good system of rehabilitation. These are examined below.

Relationships Between Professionals and Users

Service users appreciate practitioners who are direct, clear and respectful; who clarify their own experience and credentials and establish a mutual frame of reference. They expect information, advice and/or counselling where appropriate, as well as treatments, therapies and other practical help. They expect problems to be identified and preferred solutions negotiated with themselves, ensuring that distinctions are made between what is desirable and what can be offered. They want priorities for action to be agreed and a timetable drawn up. Actions need to be implemented as promised and checks made on outcomes.

Users prefer a single key worker, provided that that person knows what they are doing and that they really understand the problems and are genuinely interested in users' opinions, perceptions and views. Continuity of personnel through different episodes of rehabilitation is also important, as are arrangements for users to telephone for help when the unexpected happens. Different members of staff should share philosophies and communicate well, avoiding giving conflicting and competing advice.

Location of Rehabilitation

There was general agreement that, in most instances, rehabilitation is best undertaken in the context in which new skills or knowledge are to be applied. Thus, it is usually inappropriate in acute medical or surgical ward settings and much more likely to be effective in or close to people's homes. There was recognition that there are some circumstances where specialist units, a half-way house or a 'place of safety' will be needed to commence rehabilitation after an acute illness or injury, preparing individuals to return home at a later date. These specialist settings can be particularly important for people who have suffered a traumatic injury, such as spinal or head injury, and who need access to

special skills and technology which are concentrated in regional centres. They can also be beneficial to people whose home circumstances may inhibit the rehabilitative process, eg: older people living alone in poor accommodation who may need a short period of intensive support following surgery. Good liaison between special units and local community-based staff then becomes vital to ensure that service users continue to retain control over their own lives, and have the opportunity for periodic recall to specialist units where necessary.

Team Working

In most cases, team working will be required to achieve effective rehabilitation. Effective teams are multi-professional in nature and genuinely inter-disciplinary in the way that the different team members work together. Responsibility and accountability for the work of the team (as opposed to the individual professions represented in the team) is transparent and team leadership is exercised by individuals possessing the necessary skills and attributes (rather than being assumed to be the preserve of the medical profession). Good team working can be encouraged through team performance reviews rather than relying on individual performance reviews.

Collaboration Between Agencies

As individuals move between hospital and community services, efficient referral and information systems are needed to ensure continuity of support and the effective delivery of comprehensive care packages. Collaboration between primary and secondary health care agencies and with local government agencies such as social services departments, is an essential feature of good practice in planning, developing and purchasing rehabilitative services. Such collaboration enables common interests to be addressed, and scarce skills and financial resources to be shared or pooled.

Co-operation across the health and social service boundary increases opportunities for rehabilitation among people who might otherwise have had no alternative but to enter long term care. Short stay residential units, offering help in building confidence and skills required to return home following treatment in hospital, have demonstrated how investment in rehabilitation can pay dividends in terms of individuals' quality of life, reduced readmissions to hospital and entries to residential or nursing homes.

Collaboration between health and social care practitioners requires a much more active therapeutic approach on the part of social services staff than has sometimes been the case in the past. Good practice involves social services staff spotting problems and making intelligent referrals to their colleagues in the health service. It may also involve working alongside health colleagues in joint rehabilitation schemes and programmes. This kind of collaboration can only take place if social services staff are encouraged to identify clients who might benefit from rehabilitation and are made more aware of what can be achieved by medicine and allied disciplines. Conversely, health care staff require support for their efforts to tap into unmet need and a greater awareness of the contribution that may be made by social services colleagues.

There are merits in targeting these collaborative efforts on particular groups of social service clients, who may be living at home, in warden assisted housing, or in residential care homes. Many of these clients will be older people suffering from depression, incontinence and mobility difficulties (often leading to falls and broken bones). Many can be helped and, while a cure is not always possible, success can be demonstrated in preventing deterioration and achieving measurable improvements.

Performance Review

There were suggestions that management techniques designed to monitor the performance of different departments, agencies and work teams should focus on performance indicators that relate to outcomes for individuals. Gathering information of this sort (rather than information relating solely to rates of activity, care episodes, etc) is considered to be more useful for measuring success and more relevant to the task of improving effectiveness.

Furthermore, there were concerns that failures to introduce appropriate monitoring processes result in service providers' non-compliance with requests for information or, at best, half-hearted efforts to 'feed the beast of bureaucracy'.

Concluding Remarks

It is clear from these discussions that there are some serious concerns about the current availability and quality of services facilitating rehabilitation. Those concerns have perhaps been most graphically articulated by people's experience on the front-line. The level of detail about rehabilitation practice provided by service users and providers has been greater than that concerning policy development and strategic commissioning. While a range of problems have been highlighted, the picture painted of rehabilitation opportunities is by no means bleak. Good work is going on and people are keen to learn from experience, to improve provision and to play their part in changing things for the better.

SECTION TWO

REFLECTIONS ON ISSUES ARISING

In this section, we consider the issues raised in our discussions about rehabilitation and comment on their significance for the future development of policy and practice in this area.

The Policy Context

It is clear that rehabilitation is rising on the community care policy agenda. The people who took part in our discussion group are not alone in showing their interest and concern about the current state of rehabilitation provision. Similar discussions are evidently taking place elsewhere within the NHS, local authorities, private and voluntary organisations and central departments. Furthermore, the subject appears to be exercising the energies of people who confess that a few years ago they would have had little or no interest in rehabilitation.

The priority currently being given to rehabilitation issues has a different resonance when applied to different age groups. While financial and moral pressures are pushing rehabilitation up the priority list for young and old, there is no doubt that financial concerns figure more prominently in debates about the care of older people.

Financial Pressures

There are concerns about escalating expenditure in services for older people and expectations that greater investment in rehabilitation would achieve cost savings, or, at least, better value for money. There is a widespread belief that rehabilitative provision has been deteriorating over the last decade. That deterioration has been caused by a polarisation of services into acute and long term care. Something in the middle, promoting rehabilitation and recovery, seems to have been lost or at least to have contracted. This

contraction has begun to concern central government, the NHS and local authorities, who fear that, with few alternatives to acute or long term care, they are in danger of being locked into unnecessarily high levels of expenditure associated with frequent readmissions to hospital, resettlement in nursing or residential care homes and complex packages of domiciliary care. This is seen as neither cost-effective nor beneficial to many of the individuals concerned, who have been left to lead more dependent lives than they need to. In this context, investment in rehabilitation appears to offer an opportunity to create what the Audit Commission calls a 'virtuous cycle of expenditure'.*{1}*

Historic Neglect

The analysis regarding younger disabled people takes a rather different form. At a policy level, there is little concern about 'escalating expenditure' when the numbers of people needing support are small in comparison with the ageing population. Financial pressures are less important here than moral concerns about the quality of provision available, especially for people with multiple and complex disabilities. Opportunities for rehabilitation of this group have been regarded as problematic for decades. Within the health service, provision for this group has always operated on the margin of mainstream health care and, while this marginality may have been exacerbated by shifting responsibilities across the health and social care divide, concerns about the current state of provision are, in a sense, highlighting a policy vacuum regarding levels of support considered necessary and desirable for these individuals and their families. This may explain the anger and despair expressed by service users and practitioners in our discussion group, who believed that current provision is a product of historic neglect and under-investment.

Evidence of Decline

With regard to patterns of expenditure, there is little hard evidence to support the notion that opportunities for rehabilitation have been declining or that increased investment in this aspect of care will be a cheaper or more cost-effective option. As rehabilitation is a process rather than a designated set of services, it is not possible to track changes in levels

of expenditure or activity in the way that is used, for instance, to monitor trends in residential or nursing home care. Similarly, while there are some small-scale studies{2} assessing the cost-effectiveness of short stay rehabilitation units, these do not add up to a convincing case on the merits of increasing investment in rehabilitation on a wider scale and in the longer term.

However, it is easy to see why these issues have such strong appeal. A decline of rehabilitation opportunities seems likely to observers of trends in health and social care services. Hospitals have reduced markedly their continuing care beds and have succeeded in achieving faster throughputs in the use of acute care beds. Social Service departments have been concentrating their efforts on caring for people with high dependency needs and making preventative work a lower priority. It therefore makes sense to assume that opportunities for rehabilitation have been driven down by other more pressing priorities affecting the NHS and local authorities. In these circumstances, unease is perhaps bound to emerge with a growing sense that the main driving forces affecting health and social services are creating their own perverse incentives and that some adjustment is required to achieve a better balance in the overall health and social care system .

Continuing Care Agenda

Rehabilitation, having been low on the policy agenda for some years, is thus attracting increasing attention and interest. As a priority issue, it has been given a boost by the Department of Health's guidance on continuing care{3}, which addressed uncertainties about the role of the NHS in financing and providing a range of services to support people with long term illness or disability. This guidance reaffirmed that the NHS has a clear responsibility for, among others, services aiding rehabilitation, and encouraged health authorities to invest (or reinvest) in such provision. An additional boost was provided by the House of Commons Health Select Committee's investigation into the funding of long term care{4}, which recommended that Social Services should increase its own rehabilitation activities, implementing models of service that have demonstrated how older

people can be helped to return to their own homes with minimal amounts of support following a stay in hospital.

The Changing Policy Climate

After a long period on the sidelines of health and community care, rehabilitation is being rediscovered. Moreover, it is also apparently uniting a range of political, professional and consumer interest groups in a shared analysis of problems afflicting health and social care services and a common search for ways out of an intractable problem. This shared interest, marked by common agreement that neglect of rehabilitation has taken place on both sides of the health and social care divide and by a recognition of the mutual benefits which will result from future investment in this area, suggests that there may now be a climate in which the NHS and local authorities might work together purposively on a joint service development agenda.

This changing climate has already begun to concentrate the minds of service providers, who have been quick to spot gaps in this market. Believing that an expansion in services promoting rehabilitation may be imminent, some NHS Trusts, social services departments and independent agencies are responding in an opportunistic way by putting forward ideas for new services. More strategic responses from local policy-makers and service commissioners are, as yet, less evident; although, to judge by our consultations, there are some encouraging signs that future developments in rehabilitation are being viewed within the context of overall care systems rather than as isolated, stand-alone service developments.

Other policy developments are combining to strengthen the case for greater investment in rehabilitation and to increase the chances of change taking place in the way services are currently configured. There are clear overlaps with recent reviews of intermediate care*{5}* and the role of preventative services for older people in community care*{6}*. Policies promoting a primary care-led NHS*{7}* would also be consistent with any new drive to promote holistic rehabilitative approaches in the care of people with long term illness or disability, in a service system that maximises opportunities for independent living and

avoids unnecessary and inappropriate use of hospitals and care homes. Recent legislation, permitting local authorities to make direct payments enabling younger disabled people to buy the goods and services they require for independent living, may also result in this group having greater control over opportunities for rehabilitation.

The Parameters of Rehabilitation

It is extraordinarily difficult to have any meaningful discussion about rehabilitation when it means so many different things to different people. Moreover, this difficulty hinders decisions concerning action that might be taken to improve the current situation, regardless of whether that action entails further investigation of the problem or proposals for service development.

Definitions in a Spectrum of Care

As we showed earlier in this report, definitions of rehabilitation vary enormously. The term is often used in a very narrow sense, relating, for instance, to particular therapies used to enable an older person who has just had a hip replacement regain the ability to move about with confidence following an earlier period of pain and inactivity. Here, opportunities for rehabilitation are located in the health service and the process involves a finite period of a particular therapy designed to restore the ability to walk unaided. At the other end of the spectrum, rehabilitation, in its broadest sense, involves complex packages of support designed to enable, for instance, a person paralysed through spinal injury to achieve independent living and preferred life styles. Here rehabilitation goes way beyond the health service, requiring contributions from social services, housing, education, employment and income support agencies as well as changes to the physical environment. In its broadest sense, it can become difficult to distinguish the process of rehabilitation from other forms of support that maintain disabled people in the community.

For our purposes, we felt it was important to locate rehabilitation in a spectrum of care, where it can be distinguished by its function and purpose from acute care and long term care. With this in mind, we thus defined rehabilitation as a process that aims to restore

personal autonomy in those aspects of daily living most relevant to service users and their families. As such, it involves the use of appropriate and available medical treatments, therapies, prosthetics, social and environmental supports, and is likely to require the collaboration of health, social services and other public agencies.

Conceptual Framework

Nevertheless, different interpretations and meanings make for confusion and misunderstanding. In the absence of a clear conceptual framework mapping out the key components of rehabilitation, common themes within multiple definitions and core principles within philosophies of rehabilitation, the topic can look too difficult to comprehend and too overwhelming to tackle in any constructive way.

Creating a better map describing rehabilitation will not, of course, put an end to different interpretations, but it would enable those who wish to see improvements in this aspect of care to clarify more precisely what it is that needs to be improved. It would also enable development activity to be focused on those parts of the "rehabilitation map" that appear to be particularly problematic and where there is reason to believe that targetted interventions would make a difference.

User Voices and Professional Agendas

The picture painted by our discussion group of a historic deterioration in opportunities for rehabilitation, coupled with the rise of some exciting new service developments, reflects the views of people with very different perspectives. While there was undoubtedly a consensus about the current state of rehabilitation that cut across these different perspectives, it is not clear how far the concerns and hopes expressed were skewed by any imbalance in the makeup of the discussion group.

Inevitably, service providers and commissioners talk about problems and progress as seen in their bit of the service system. These partial views can distort the overall picture or at least make it incomplete. Users and carers are likely to have a different and possibly more comprehensive view as they experience many different aspects of the service system.

Furthermore, their accounts of needing and obtaining help, of how they are treated by practitioners and of the impact on their lives of any help provided, have a unique authenticity that contrasts with accounts made on their behalf by others.

Hearing Users' Views

Unfortunately, the voices of users and carers in our discussion group were weaker than those of professionals. This, of course, reflects the nature of invitations issued to join the group and the availability of particular individuals on the day in question. Nevertheless, it was clear that, while the voice of young disabled people in work could be heard loud and clear, the voices of older people and their families were much more muted. To be sure, advocates spoke on their behalf - often with great passion - having formed their views through working in voluntary organisations representing older people's interests or through direct contact with older patients or clients using statutory services.

In our view, more needs to be done to hear the powerful stories of users and carers, in order to understand more clearly what from their point of view is working well and where there is room for improvement. These stories may, of course, confirm what professionals are saying but they may also challenge both the perceptions and assumptions being voiced by some professionals.

Professional interests

It is particularly important to strengthen the voice of users and carers at a time when professional agendas can all too easily colour debates about service change. As calls are made for an increase in rehabilitation opportunities, it would not be surprising to see a certain amount of jostling for position taking place among practitioners and managers who can see new business opportunities and scope for building (or rebuilding) empires. Nor would it be unusual to hear service providers justifying traditional approaches to rehabilitation which are currently being questioned or indulging in special pleading to promote their own professional position and status. The tribalism that bedevils health and

social care might also become more apparent as particular provider groups pay off old scores and seek to enhance their power and influence.

Of course, these professional interests need not necessarily be at odds with the interests of people who are ill and disabled. Indeed, some of the ideas put forward by professionals for building a better system of rehabilitation have clearly arisen from their own anger and dismay at provision that they see as failing to meet the needs of disabled people. These same professionals often reveal a strongly felt sense of injustice, neglect and waste as they describe current services. Many of their proposals for change would no doubt help people in need, while at the same time strengthening their own professional standing and the services that they care about so passionately. The point here is not therefore to dismiss the views of service providers but to treat them with some caution and to examine the extent to which they confirm or conflict with the views of other interest groups.

User Focus and Boundary Working

We are convinced of the imperative to retain a focus on individual need as a steer to policy and service developments in rehabilitation. This user or patient-centred focus is necessary if we are to move away from historic patterns of rehabilitation which have grown up over the years around particular facilities, professional skills and categories of disease or disability. This will require a renewed emphasis on needs assessment, on packages of support enabling independent living and on key workers to co-ordinate and oversee rehabilitation packages.

Everything we have heard about people's experience of good practice in rehabilitation indicates that good outcomes for service users are much more likely to be achieved when professional and agency boundaries are crossed. Moreover, good liaison and joint working across those boundaries are essential if the assessment process is to be successful in picking up disabling conditions that can be treated, eg: depression, incontinence, etc, and identifying individuals' potential for regaining a level of independence that enables them to regain maximum control over their lives.

Evidence-Based Commissioning

We have heard powerful arguments being put forward for increased investment in rehabilitation. It is not clear where additional funds for new developments might be found, other than by shifting resources from acute and long-term care services. There are also barriers that will need to be overcome in the way provision is purchased. There are undoubted difficulties in translating into the commissioning process the political rhetoric that promotes patient or client-focused care and advocates that funding should follow the individual. The reality of commissioning is one of eligibility criteria, targets and inappropriate contract currencies - all of which can mitigate against a rehabilitation process emphasising user-defined goals and a flexibility required to meet individual need.

However, questions about the future shape of rehabilitation do not revolve solely around the availability and allocation of finance. There are perhaps more difficult questions to be answered about the kind of provision that ought to be commissioned and the priorities that need urgent attention.

Investment Strategies

The discussions that led to this report suggest to us that investment decisions cannot be a matter of spending more or less on a historic pattern of provision. There is a complex planning and development agenda which will need to be taken forward at national and local levels in order to achieve significant success in improving the range, availability and quality of rehabilitative services. Commissioners, who are likely to have relatively little knowledge of this area and even less experience of contracting for rehabilitation, could probably benefit from informed advice on the action needed to improve on current provision. The Department of Health's forthcoming "Rehabilitation Handbook"*{8}* may prove helpful in this respect.

We are mindful of the fact that commissioners are under pressure to base their purchasing decisions on evidence of service effectiveness and value for money. We support the notion that decisions regarding the design and development of services promoting

rehabilitation should be based on evidence of effectiveness, provided that what counts as evidence is not defined too narrowly by, for instance, relying solely on findings from control trials. We are nevertheless aware of a tendency on the part of some commentators to demand more exacting standards on evidence regarding preventative and rehabilitative provision than is currently accepted in relation to acute services. This is inconsistent and could lead to a misallocation of resources.

At the same time, we understand that, in real life, it is easier to justify investment in existing patterns of service than it is in new service arrangements. Where the evidence for change does not exist or is weak, there is little to encourage increased investment.

We conclude therefore that there is much to be done to collate and disseminate in a useable form existing evidence that shows what organisational arrangements and professional practices have been found to be effective in terms of outcomes for individuals. At the same time, we should like to see investment in new service developments which would evaluate the merits of new ways of working and the benefits to service users and their families and the organisations financing or providing that support.

With access to more objective measures of benefit, both purchasers and providers would have stronger incentives to invest in service development.

Commissioning Decisions

We appreciate that we have only a limited understanding of how service commissioners, including health authorities, GP fundholders and social services departments currently make decisions about rehabilitation. It would perhaps be helpful to take a closer look at decision-making among commissioners, examining especially how `front-runners' in this field are planning or beginning to change the face of rehabilitation in their area.

In the meantime, we note the potential for health and social care commissioners to work together to enhance opportunities for rehabilitation. Both now have a mutual interest in finding ways to enable people to return to independent living where possible and to avoid

unnecessary use of acute and long term care provision. There are, we believe, exciting prospects for joint commissioning of this aspect of care.

Human Resource Issues

We are not persuaded by claims that developments in rehabilitation are being held back by shortages of specialist staff. We are not sure how such claims might, in any case, be substantiated. On one level, it would be possible to look at shortfalls in staffing establishment, but this would not in itself be convincing in the absence of information about the appropriate use of specialists as opposed to generalist staff, and the ways in which they are currently deployed to deal with demand.

We suspect that it may be more illuminating to consider roles, responsibilities and relationships among specialists and generalists. Demand is such that there is great scope for specialists in rehabilitation medicine and allied therapies to play a greater part in advising, educating and supervising others (including nursing staff, care assistants and family carers) in therapeutic activities.

This suggests that quite radical changes in the education and training of health and social care staff will be required. These changes will be necessary to increase expectations about people's potential for rehabilitation and to improve awareness of effective rehabilitation processes. Where education/training is undertaken in multi-professional settings, that can only be helpful, improving understanding about respective roles and responsibilities and building trust and confidence across professional boundaries. In order for specialists to be more effective in sharing their knowledge and skills, they will need opportunities to develop their own confidence as educators, advisors and supervisors.

Concluding Remarks

Our reflections on issues arising from our consultations indicate that we are witnessing a sea-change in attitudes towards rehabilitation within health and social care sectors. Hopes appear to be running high about the benefits of increasing investment in this aspect of care.

At the same time, there is a fair amount of confusion and uncertainty about the current situation and future prospects regarding rehabilitation. Greater clarity on both counts will be necessary in order to inform development strategies.

SECTION THREE

WHAT NEXT? MOVING TOWARDS A REHABILITATION DEVELOPMENT AGENDA

Everything we have learned from this preliminary investigation suggests that the climate is right for pursuing a strategic approach to service developments facilitating rehabilitation. However, our discussions about rehabilitation reveal that this is a complex service issue, where further work is needed in order to ensure that future development initiatives are conceptually sound, focused on clear and achievable goals and capable of attracting support from the many political, managerial, professional and lay interests who have a stake in this aspect of care. We therefore propose that further work in this area should be undertaken in two stages. The first stage is designed to clarify where developmental effort could most usefully be focused, while the second stage involves the implementation of a service development strategy which will improve opportunities for rehabilitation on a nation-wide basis.

Stage One will help shape a subsequent development strategy. It will involve the following activities:

- **A literature review** should be commissioned, pulling together evidence which can be used to back up or challenge the views, beliefs and ideas that have emerged in discussions about rehabilitation policy and practice. The review should lay out a conceptual framework to guide developments in rehabilitation and should explore questions about responsibilities across the health and social care boundary of community care; about trends in the availability and quality of rehabilitation; and about

the impact of different organisational arrangements, practices and modes of financing and commissioning rehabilitation services.

- **Further consultations with users and carers** should be undertaken in order to involve them more fully in future developments. It will be especially important to consult people who have tended to be neglected in the past. Thus efforts should be made to capture the experience and views of people with complex disabilities who may be resident in units for young disabled people, head injury units, etc, or who live at home with 24-hour care, and older people with chronic illness and long term disability.

- **Collecting examples of service models** that are being put into place and analysing their significance for strategic service development.

Stage Two

- **A nation-wide service development initiative** should be mounted, focusing on specific aspects of the rehabilitation 'territory' that need to be improved (these should emerge from Stage One). This initiative should encourage and support local agencies to test out new ways of working and to implement schemes of proven worth.

- **A network of individuals and agencies** should be supported and further developed, providing opportunities for information exchange on innovation and good practice.

- **A nation-wide dissemination strategy** should be developed to spread information on development work in progress, on the lessons being learned and the implications for wider implementation. This strategy should encompass ways of reaching service agencies, managers and practitioners (through, for instance, workshops and conferences, briefings, newsletters, etc) and the public at large (through the mass media and relevant magazines).

The King's Fund aims to take forward this programme, in partnership with other interested national, regional and local bodies. In co-operation with the Audit Commission, we have already jointly commissioned a literature review and will make it available to other interested bodies early in 1997, when it is due to be completed.

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